

hospice UK

Dying Behind Bars

How can we better support people in prison at the end of life?

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For more information

For more information about this work please contact the Policy and Advocacy team at Hospice UK by emailing policy@hospiceuk.org

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About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

About hospice care

Hospices seek to improve the quality of life and wellbeing of those with a life-limiting or terminal illness, helping them live as fully as they can for the time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs. Hospices are rooted in their communities they serve, with each service developed to reflect the needs and the context of its local area. Hospices provide expert care for those in need as well as their family and carers, and care is free at the point of access.

Hospice providers offer a wide range of services to people in their homes, in day services or outpatient clinics, into care homes and hospitals, and through inpatient hospice care. The majority of care provided is to people in their own homes or attending the hospice, rather than just inpatient care.

A note on terminology:

- **Palliative care** is the treatment of patients with an illness for which a cure is no longer possible, the World Health Organization defines it as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." [i]
- **End of life care** is understood as palliative care given in the final year of life, focusing on patients' comfort, enabling a dignified death, and supporting their families and loved ones.
- **Hospice care** encompasses all of these elements, focusing on the person as a whole (see Figure 1[ii]). Hospice UK states that "Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different." [iii]

With their common focus on caring for individuals facing the end of life, these terms will be used interchangeably in this report. [iv v]

- **The terms "prisoner" and "offender"** will be avoided where possible in this report, as it has been shown by both people in prison and those who work closely with them that referring to them as such can be dehumanising.

This report will instead use the terms "people in prison," "imprisoned people," "incarcerated people," or simply, "patient."

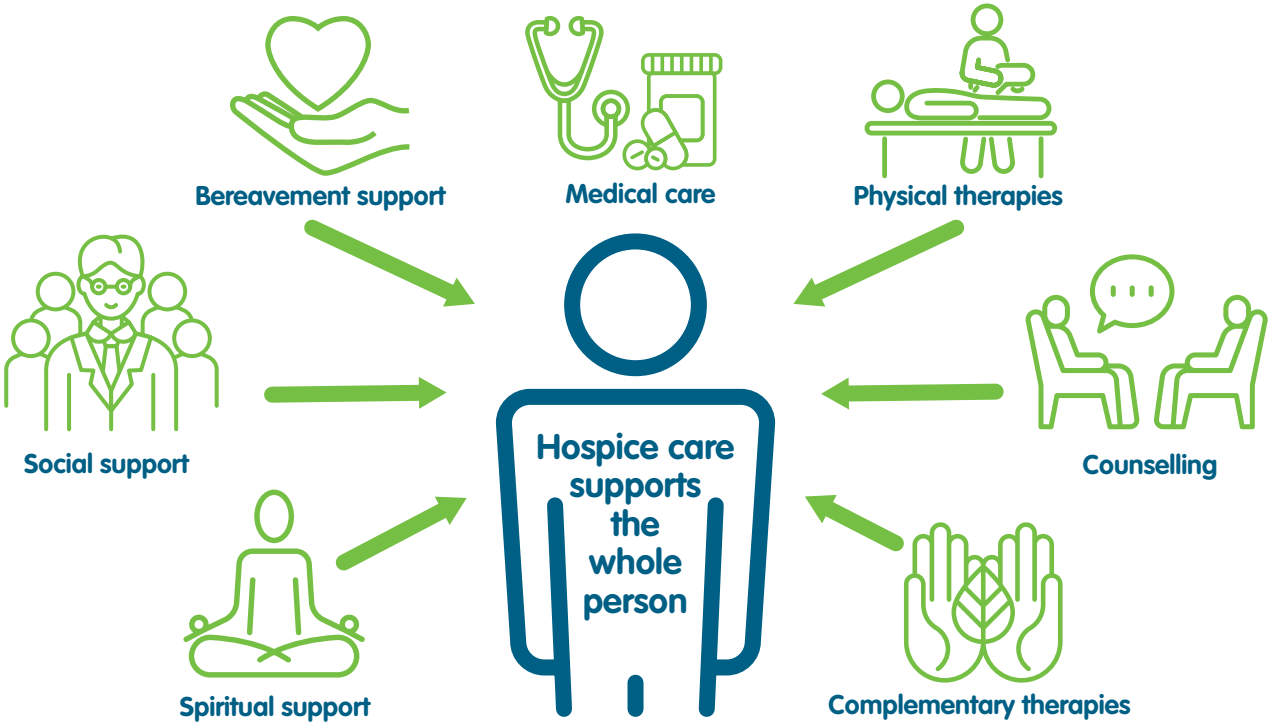


Figure 1: A Hospice UK infographic demonstrating how hospice care supports the whole person

Foreword

We are grateful to Hospice UK for producing this pivotal report. Too often end of life care is an area of care delivery which goes unnoticed by many. People in prison are not always perceived as a deserving population or indeed see themselves as worthy of good care. And arguably prisons and the people who work so hard in them form the least visible, most neglected, of our public services. The welcome emphasis in this report is on common humanity and inclusion. People in prison are people and often people with unmet health needs. They are part of our community.

Incarceration, and associated loss of liberty, is the punishment for crimes committed. Denying the same health and care services that any of us may need is not. Health inequalities within the prison population are stark and present major challenges to hard-pressed health and justice services. The legal principle of equivalence in healthcare is the bedrock for many of the improvements proposed in this report. We should expect uniformly high standards in the services available and the creativity and flexibility that allows clinicians to be able to deliver patient-centred care in a holistic way. We know this is possible.

There are many challenges in the delivery of compassionate end of life care. This practical report not only considers the challenges, it also describes some positive and innovative solutions. These range from inspiring buddy systems to the support offered by hospices to patients and staff within prison settings as well as the compassionate care offered within hospices themselves. It also places a refreshing, and entirely appropriate, emphasis on patient consultation and choice – a familiar concept within healthcare but less usual within prison settings.

In September 2020 the Independent Advisory Panel on Deaths in Custody and the Royal College of Nursing published *Avoidable Natural Deaths in Prison Custody: Putting Things Right*. Many of the recommendations from our report overlap with, and complement the work of, Hospice UK. There is consensus that we need to improve end of life care across the prison estate. Specifically this includes the reassessment of Do Not Resuscitate decisions, a review and overhaul of the system for compassionate release, a review of application of the Care Act in prisons and implementing the 'Dying Well in Custody' Charter to maintain dignity, better support families and deliver consistently good palliative care.

Rapidly rising numbers of elderly people in custody, many with chronic underlying health conditions, ever-lengthening prison sentences and the impact of premature ageing, all mean that many people will need end of life care. It is all too easy to see innovation in practice lost due to funding restrictions or overly bureaucratic processes which can be better organised to meet people's needs. With both reports calling for action and commitment, we know that many justice and health practitioners and policy makers and voluntary sector partners are determined to bring about real improvements that are sustained over time.

Ann Norman, Justice and Forensic Nursing Professional Lead, Royal College of Nursing
Juliet Lyon CBE, Chair, Independent Advisory Panel on Deaths in Custody

Executive summary

"Within the prison system are remarkable people working tirelessly in impossible circumstances. I saw real compassion in action, tempered by an outdated, nebulous bureaucracy which was never designed to provide for prisoners at the end of life… With a prison population increasing in size and frailty along with prison sentences which are growing longer, society needs to very carefully consider how it provides for its most vulnerable members."

Testimony from a palliative care doctor working with imprisoned patients

Of the estimated 400,000 people a year across the UK who require palliative and end of life care, a quarter do not have their needs met.[vi] Research consistently indicates that access to hospice and end of life care is unequal,[vii] this report demonstrates that for the prison population, this inequality of access can be particularly acute.

It is a critical time to focus on imprisoned people. The number of over-60s in the prison population has more than tripled in the past two decades, and in the past ten years alone, deaths in prison due to natural causes have increased by 77%, with older people accounting for over half of all deaths in custody. 90% of the older prison population have at least one moderate or severe health condition.

This significant rise in deaths, together with an increasingly sick and older prison population, has led to a corresponding rise in need for end of life care, a need that this report demonstrates is not being adequately met.

This report uses in-depth analysis of the Prisons and Probation Ombudsman's Fatal Incident reports, as well as close engagement with hospice services and other health and social care providers who support imprisoned people at the end of life. Among the challenges this report identified were the widespread inappropriate use of restraints, delayed or absent consideration of compassionate release, and care that did not make use of the skills and specialisms available from the health and social care sectors.

Recommendations, which can be found on page 11, include calls to review the compassionate release process and action to ensure imprisoned people with protected characteristics are given due consideration.

As those supporting and championing high quality palliative and end of life care for all, we must take action to ensure this unacceptable state of affairs changes. A prison sentence is the deprivation of an individual's liberties, it is not a sentence to poor health and social care.

Purpose of this report

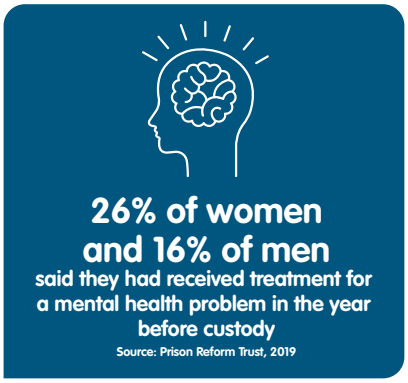
Imprisoned people are considered to be an inclusion health group, i.e., a group that faces the sharpest edge of exclusion and marginalisation, and as a result, particularly poor health outcomes.[viii]

Certain lived experiences tend to present across inclusion health groups, such as trauma, poverty, and domestic violence.

These experiences are then compounded when many within these groups face multiple barriers in accessing health and social care services due to fear, stigmatisation, discrimination, past experiences of being turned away, and punitive social policies.[ix]

This can lead to a vicious cycle of health deterioration, that health services are not always equipped to deal with.[x] This report demonstrates that the current need for end of life care for imprisoned people is not being adequately met, and that given prison population projections, this must be addressed as a matter of urgency. By improving outcomes for those facing the most acute forms of exclusion, systems improve for everybody who needs to access them.





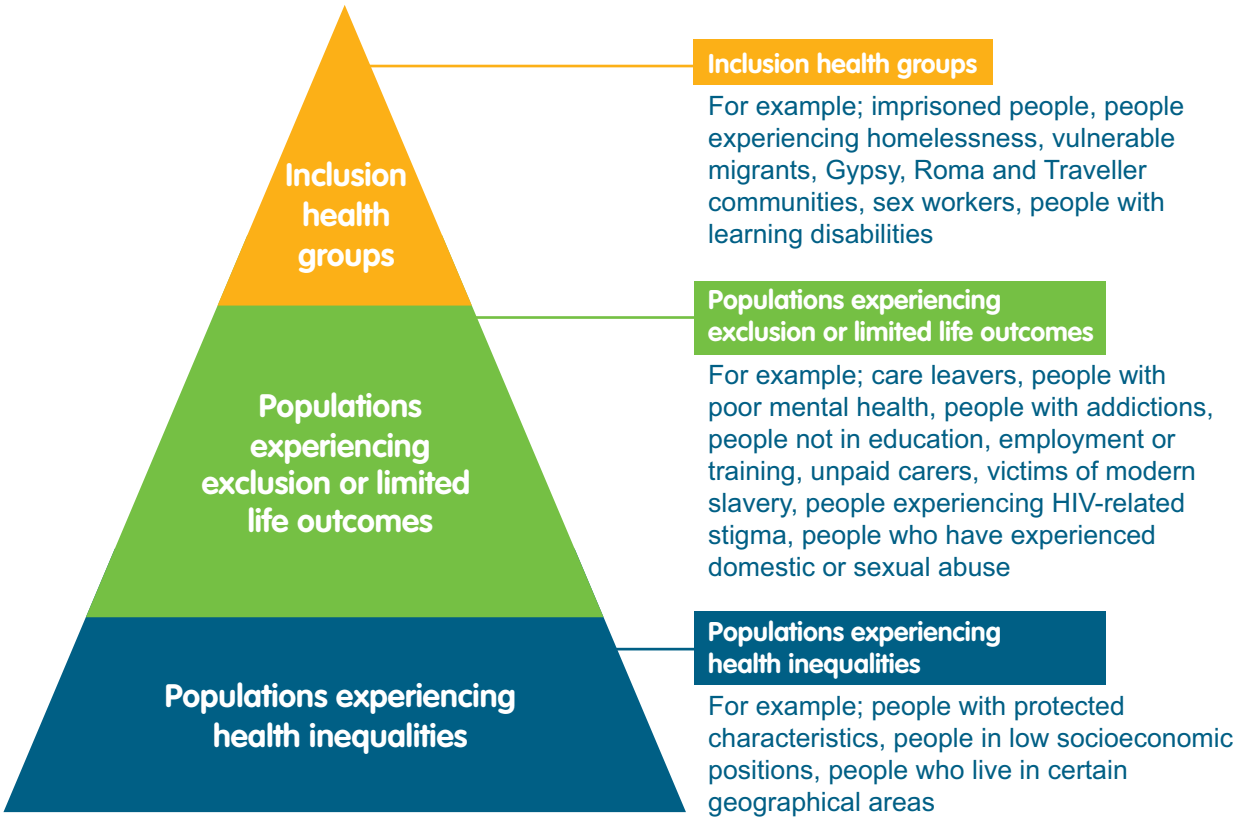


Figure 2: A diagram demonstrating the acute nature of poor outcomes experienced by inclusion health groups, and how improving the care received by these groups can improve care for others
Source: Adapted from a diagram created by Sarah Sweeny, Policy and Communications Manager at Friends, Families and Travellers

Additionally, the general public are in favour of improving end of life care for imprisoned people. A poll conducted by Opinium Research on behalf of Hospice UK demostrates that:

Thinking about end of life care for terminally ill imprisoned people, three in five (59%) British people would support better provision if they knew if could reduce avoidable suffering. Over half (56%) of British people feel terminally ill imprisoned people should have the same right to access high quality end of life care as the general public.

With this in mind, this report aims to:

1. **Examine the current state of the end of life care received by people in English prisons.**
2. **Outline the provision of end of life care in prisons, with particular focus on the work of hospices and other charitable organisations.**
3. **Understand the unique challenges that end of life care providers face when delivering support to people in English prisons.**
4. **Establish what different stakeholders – including Government, end of life care providers, the broader end of life care health and social care sectors, and national organisations can do to improve the end of life care received by incarcerated people in English prisons and their loved ones.**

Introduction and background

The prison population is growing older and sicker.

The number of incarcerated people aged over 60 has **more than tripled** in the past twenty years.[xi] **90%** of the older prison population have at least one moderate or severe health condition.[xii]

These sharp demographic changes have led to a startling outcome: prisons are now the UK's largest provider of residential care for frail, older men.[xiii]

As a result, increasing numbers of people are dying behind bars.

In the past decade, deaths in prison due to natural causes have increased by 77%, with older people accounting for over 50% of all deaths in custody.[xiv]

This significant rise in deaths, together with an increasingly sick and older prison population, has led to a corresponding rise in need for end of life care.

This need for end of life care for imprisoned people is not being met.

Defining "older" in the context of prison

The age at which incarcerated people are considered "older" is contentious.[xv]

Outside of prison, "older" is generally deemed to be the age of 60 and over. In England and Wales, Her Majesty's Prison and Probation Service (HMPPS) has adopted the age of 50. It is argued that in prison, this threshold decreases to 50 and over, as incarcerated people have a physical health status that is ten years older than their non-incarcerated counterparts.[xvi] Evidence indicates that incarcerated people aged 50 and over experience accelerated physiological ageing in relation to chronological age.

This is thought to be the result of health inequalities, socio-economic indicators of health prior to imprisonment, as well as the health impact of incarceration itself.[xvii xviii xix]

This report's use of the term "older" will denote people in prison aged 50 or over.

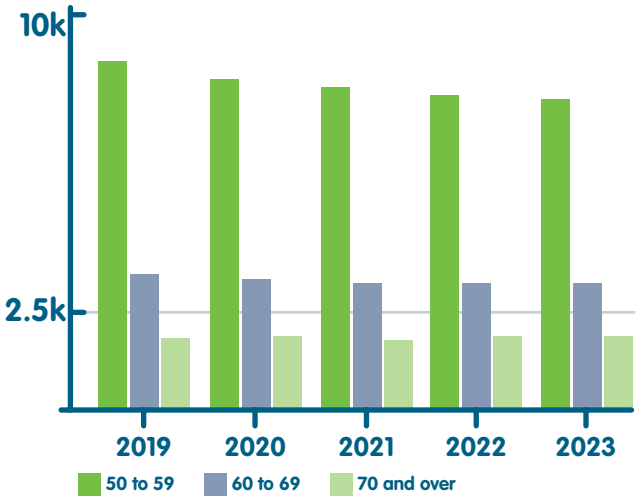
The ageing prison population

There can be no doubt that the prison population in England and Wales is a rapidly ageing one, and that this older cohort has substantially increased over the last 20 years. In England and Wales, over 50s now account for one in six people in prison.[xx] (see Figure 3.[xxi]).

Over 60s are the fastest growing demographic among the prison population,[xxii] increasing by 243% from 1,511 in June 2002 to 5,176 in March 2020.[xxiii] This is a trend that is set to continue.[xxiv]

In the same time period, the 50-59 age group has more than doubled; increasing from 3,313 to 8,588.[xxv] This group is expected to increase to 14,800 by June 2021, a much sharper trajectory when compared with younger imprisoned people.[xxvi]

Figure 3:
Prison population aged over 50, 60 and 70 years old. June 2019 actuals and projected to June 2020-23



What has caused this?

The ageing prison population is not due to an "elderly crime wave." Rather, it is the result of several factors, including:

- Harsher sentencing practices: this "sentence inflation" means that increasing numbers of people are receiving prison sentences and these sentences are getting longer;[xxvii]
- A rise in the number of convictions for sexual offences, including an increase in historic sexual offences convictions meaning people are entering prison at older ages; [xxviii] and
- The absence of consistently timely and transparent processes when it comes to compassionate release, by which people can be released from prison for compassionate reasons including if they have a terminal illness and are soon approaching death. [xxix]

The increasing need for end of life care

Research indicates that up to 90% of older incarcerated people have at least one moderate or severe health condition, with over half having three or more.[xxx] Troublingly, their health outcomes are worse than those of the same age outside of prison,[xxxi] despite being entitled to the same healthcare and treatment.[xxxii]

In the 12 months up to June 2020, there were 218 deaths in prison categorised as due to natural causes across England and Wales, a 77% increase compared to a decade prior.[xxxiii]

With growing numbers entering prison later in life with long sentences and multiple severe health conditions, come growing numbers of people dying with palliative care needs while incarcerated. The need for end of life care, therefore, is and will continue to grow more acute.

We recognise the current considerable partnership working that enables prison health and care provision and the opportunities and challenges this can present. With this in mind, we make a total of nine recommendations that address both the prison system and the wider end of life care sector.

Our recommendations

Recommendation 1:
The Prisons and Probation Ombudsman should comprehensively review its application of "equivalent care" and ensure that it is aligned with standards of care in the wider health and care system.

Recommendation 2:
HM Prison and Probation Service and the prison system should review their policy and practice on the use of restraints, especially concerning seriously and terminally ill imprisoned people.

Recommendation 3:
The compassionate release process should be comprehensively reviewed and amended to ensure that it is used in a consistently fair and timely manner.

Recommendation 4:
The provision of bereavement support within prisons should be established at a national level and hospice services should explore the possibility of supporting or providing this care.

Recommendation 5:
The Prisons and Probation Ombudsman should conduct an in-depth review of natural, foreseeable deaths of those with protected characteristics in prison.

Recommendation 6:
It is vital that there is a better shared understanding of the support that is available from hospice services, and the unique needs that imprisoned people will have at the end of life. National organisations and local services should commit to dispelling myths and misconceptions.

Recommendation 7:
National organisations should support and facilitate the sharing of good practice across the palliative and end of life care system for those providing care for imprisoned people.

Recommendation 8:
Hospice services should assess the need for palliative and end of life care support for imprisoned people in their community and proactively engage and work closely with local specialist organisations supporting prison health and care services to ensure that need is met.

Recommendation 9:
End of life care for imprisoned people should be a UK-wide policy priority. The current provision of and unmet need for end of life care in prisons should be established across the four nations.

This report acknowledges that many of the people referenced have been imprisoned for committing serious crimes. The general public have the right to expect appropriate protection from them. This is, however, not a reason for incarcerated people in need to not receive support.

Ultimately, a prison sentence is the deprivation of an individual's liberties, it is by no means a sentence to poorer health and care services. This includes end of life care.

Current state of affairs:
What does end of life care currently look like in English prisons?

Prisons and Probation Ombudsman (PPO) Fatal Incident reports (FIRs)

The Prisons and Probation Ombudsman (PPO) independently investigates all deaths in custody, to establish whether the treatment and care the deceased received prior to their death was up to standard. This leads to the publication of a Fatal Incident report (FIR). The FIRs identify the deceased by name and contain remarkably comprehensive detail regarding their medical histories and the circumstances in which they died. These are all publicly available.

To balance investigation times, potential publishing delays, and the need for a recent data set, all FIRs between October 2018 and December 2019 published before 1 December 2020 were examined for this report.[xxxiv]

Our analysis of all FIRs within this timeframe demonstrated that 153 incarcerated people died in England. Of these, 136 were categorised as due to natural causes. Further analysis revealed that 95 of these deaths (62%) were described as foreseeable and as requiring palliative care (see Figure 4).

These 95 FIRs were analysed against a set of criteria to evaluate the quality of end of life care the imprisoned individuals received (see Appendix A). The cases described in these FIRs are anonymised as F1, F2, and so on.

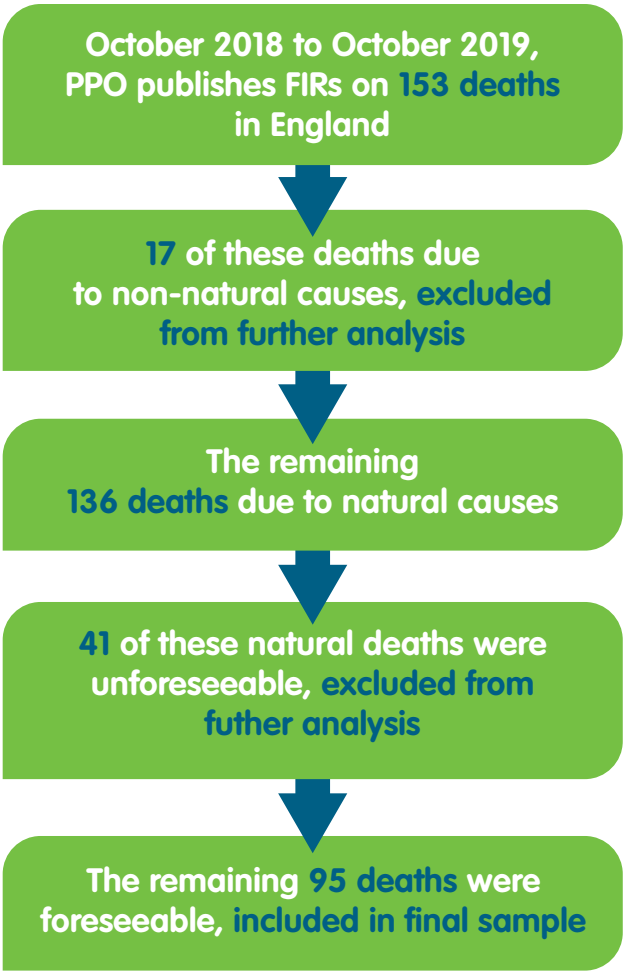


Figure 4: Diagram demonstrating how the final sample of PPO FIRs was chosen

"If hospices are about giving a voice to people who ordinarily don't have one, this work should sit at the front and centre of what we do. […] Prisoners have the same right to healthcare as everybody else."

Interview excerpt, Kate Heaps, Chief Executive of Greenwich & Bexley Community Hospice

Findings from Fatal Incident Reports

Delving deeper into the FIRs can make for grim reading.

The FIRs describe people with dementia who don't know that they are in prison, or how they got there. Frail, elderly people taken to hospital chained to prison officers and later, cuffed to hospital beds. Terminally ill imprisoned people dying in their cells before receiving the outcomes of their applications for compassionate release.

But amongst this, there are accounts of incredibly compassionate care.

From managing symptoms in the face of medication restrictions to caring for older, frail imprisoned people within an estate unfit for purpose, the challenges to delivering end of life care can be significant. In spite of this, the FIRs detail a number of cases in which prison staff and health and social care professionals, including hospice staff, have gone above and beyond to provide exemplary care in less-than-ideal circumstances.

F35: Following the patient's terminal cancer diagnosis, prison staff managed to arrange transfer to a specialist palliative care suite in another prison. The patient refused, as he wanted to stay in a prison with which he was familiar. Prison staff respected this, creating a care plan to enable him to stay. This included enlisting support from a rapid response team from Marie Cure in case the patient required medical attention outside of healthcare hours, the prescription of anticipatory medicines to manage end of life care, and a social care assessment to support his increased care needs.

As the patient's illness progressed, a specialist nurse practitioner from St Barnabas Hospice assessed his needs and together they completed an advance care plan in which a Do Not Attempt Cardiopulmonary Resuscitation Order was put in place. The patient said that his preferred place of care was the prison or a hospice, and that his preferred place of death was a hospice. His wishes were respected, and two months later, the patient spent his final days in Butterfly Hospice.

F39: The patient was diagnosed with an aggressive form of incurable cancer and while his prognosis was poor, hospital doctors were unable to provide a specific prognosis regarding his life expectancy. Because of this, prison staff were unable to proceed with an application for the patient's early release on compassionate grounds. Instead, while he was in hospital, the prison granted the patient release on temporary license to enable him to spend time at home with his family as it was clear he was close to the end of life. The prison maintained contact with his family and palliative care team up until the patient's death.

- Out of the 24 FIRs describing particularly good end of life care practice, over half were cases in which hospices were involved in delivering this care.
- In nearly a quarter of all cases (22) examined in the final data set, hospices were involved in the incarcerated people's end of life care. This care ranges from directly caring for them at the end of life within a hospice inpatient unit, to hospice palliative care consultants advising healthcare staff working in prisons, and hospice nurses assisting with advance care planning.

Our analysis indicates that while there is substantial hospice involvement within prison healthcare, it is by no means standardised at a national level. There is considerable potential to increase hospice involvement and ultimately, it can significantly improve the end of life care received by imprisoned people.

Some of the most troubling and recurrent criticisms of the care provided in these FIRs include:

1. The care being considered inequivalent to that which would have been received in the community: reported in 8 out of 95 cases.

Examples:

F94: The patient's clinical condition deteriorated while at HMP Parc with significant weight loss; he was frail, not eating, incontinent, and fell out of bed five times. In March, he had blood tests to investigate any underlying cause for leg swelling and frequent urination. He did not attend the appointments to review the results of the blood tests. The prison GPs did not make any attempt to inform the patient that he was anaemic or that the cause needed to be further investigated.

F26: There was a significant delay in prison healthcare staff implementing a Do Not Attempt Cardiopulmonary Resuscitation Order (DNACPR) for the prisoner because a GP was not available. No one followed this up, which resulted in the hospital putting a DNACPR order in place for the prisoner on the day that he died.

Troublingly, there are also numerous instances in which the care described within the FIRs is considered equivalent to that which would have been received in the community which is objectively substandard. For example:

- An imprisoned patient was inappropriately restrained until 12 hours before death despite being in a lot of pain and terminally ill (F63).
- The imprisoned patient's rapid and worrying deterioration in mental and physical condition were not recognised or treated with sufficient seriousness by healthcare staff (F89).
- The imprisoned patient's next of kin were not notified of his death until one month after it occurred (F46).

It is an indictment of the care that we receive in the community to consider the above as "equivalent."

Recommendation:

The Prisons and Probation Ombudsman should comprehensively review its application of "equivalent care" and ensure that it is aligned with standards of care in the wider health and care system.

2. The inappropriate use of restraints on incarcerated people at the end of life: reported in 20 out of 95 cases.

Examples:

F63: The patient was restrained on his final admission to hospital until 12 hours before his death, although he was terminally ill and in a lot of pain.

F46: Each time the patient went to hospital he was escorted by two prison officers; with the exception of two instances, he was double handcuffed each time. On one instance in 2017, escort officers would not remove the cuffs or leave the room as is required when carrying out a CT scan, the scan had to be postponed.

The patient's behaviour in prison had been described as "exemplary," even when he was in advanced stages of illness and having to use a wheelchair for hospital visits, he was still restrained.

F43: Prison staff used double handcuffs on the patient. Double cuffing is usually required for moving Category A or Category B people in prison in good health. The patient in question was a seriously ill Category C patient, with very poor mobility, assessed as a low risk of escape and a low risk of harm to others. It is difficult to see how the escort risk assessment could conclude that he had the ability to escape unaided from two escort officers.

When the patient was in hospital, he was restrained using an escort chain for more than a week although he was seriously ill and his mobility was very poor. It is particularly concerning that although the escort chain was removed when he had an operation, it was reapplied while he was unconscious in the recovery room. It is very difficult to understand why prison staff thought this was justified for a seriously ill and immobile Category C patient.

The inappropriate use of restraints within prisons has been a recurrent criticism for years, with the PPO stating that there are "still too many cases of prisons unnecessarily and inhumanely shackling seriously and terminally ill prisoners – even to the point of death."[xxxv]

With the increasing numbers of imprisoned people dying with serious, debilitating illness within the secure estate, it is imperative that the policy and practice on the use of restraints is overhauled as a matter of urgency.

Recommendation:
HM Prison and Probation Service and the prison system should review their policy and practice on the use of restraints, especially concerning seriously and terminally ill imprisoned people.

3. Delayed or no consideration at all of early release on compassionate grounds despite imminently facing the end of life: reported in 15 out of 95 cases

Examples:

F46: The possibility of the patient's early release was raised in 2017 when it was noted that he had less than a year to live; however, there is no evidence that the prison or clinical staff sought a formal prognosis of his life expectancy, or that they had discussed with him the possibility of compassionate release.

F86: Because of poor communication between HMP Garth and the patient's former prison, it was unclear whose responsibility it was to initiate the compassionate release process, as a result it didn't take place.

The current compassionate release process is failing those with terminal diagnoses. Of the sample of FIRs analysed for this report, there was not a single case in which an imprisoned person with a terminal diagnosis was granted early compassionate release.

The Covid-19 pandemic has thrown this issue into sharp relief; at the start of the pandemic up to 1,000 people in custody were identified as medically vulnerable and therefore eligible to be considered for temporary compassionate release. As of October 2020, only 54 have been safely released under this scheme.[xxxvi]

The current process is demonstrably not fit for purpose.

Recommendation:
The compassionate release process should be comprehensively reviewed and amended to ensure that it is used in a consistently fair and timely manner.

While only providing a snapshot of the reality of dying in the secure estate, these examples give us a troubling insight into how imprisoned people are being failed at the end of life.

Critical consideration: bereavement support

Troublingly, the FIRs make no explicit mention of bereavement care and support, either for prison officers or for imprisoned people. General support following the death of an imprisoned patient is typically referred to in the following manner:

> *After Mr X's death, the duty manager debriefed the escorting staff to ensure they had the opportunity to discuss and issues arising, and to offer support. The staff care team also offered support.*
>
> *The prison posted notices informing other prisoners of Mr X's death, and offering support. Staff reviewed all prisoners assessed as being at risk of suicide or self-harm in case they had been adversely affected by Mr X's death.*
>
> **An excerpt from a FIR referring to the support offered staff and fellow imprisoned people**

What's more, out of the 95 FIRs examined for this report, less than a quarter (22) mention this support being extended. The provision of specific bereavement support is an essential component of end of life care,[xxxvii] and more broadly, it is critical consideration for supporting mental health across the secure estate.

It is well-documented that there is a mental health crisis in prisons,[xxxviii] and with increasing numbers dying behind bars, there is a very real risk that unmet bereavement need will further exacerbate this crisis. While some of the FIRs refer to prison chaplaincy teams providing pastoral support to those affected by the death of an imprisoned person, its scope and whether this provision is consistent at a national level remains unclear.

Bereavement support is a key offering of hospice services, and the possibility of this care being extended to within prisons must be explored.

Recommendation:

The provision of bereavement support within prisons should be established at a national level and hospice services should explore the possibility of supporting or providing this care.



Critical consideration: marginalisation at multiple intersections

In committing to improving end of life care for those in prison, we must account for the intersections at which incarcerated people are marginalised on multiple counts.

Racialised groups

We must recognise that incarcerated people from racialised communities face distinct challenges whilst in prison.

They are significantly overrepresented in prison, making up 27% of the general prison population compared to 14% of the general population. Otherwise put, if the prison population in England and Wales reflected the make-up of the non-prison community, there would be 9,000 fewer people in prison, the equivalent of 12 average-sized prisons.[xi]

It is well-documented that their healthcare needs are less likely to be identified and they often have poorer relationships with prison staff and experience higher levels of discrimination across all aspects of prison life.[xiii]



What's more, incarcerated people from racialised communities are also less likely to report ill health and access services and support, because of a culture of disbelief from healthcare professionals which has resulted in missed opportunities to diagnose illness and the understandable distrust of services that this engenders.

Women

While the proportion of deaths due to natural causes is no higher for women than it is for men, women only make up 5% of the total prison population, and generally speaking, they commit less serious offences with many serving sentences of less than 12 months.[xiiv] While this translates to fewer women dying in custody, we cannot neglect the fact that women in prison have distinct needs at the end of life that may not be fully met. It has been shown that in prison, women's healthcare needs are different to men as many have higher levels of mental health problems and histories of abuse, the acknowledgment and accounting of which is essential to their care.[xiv]

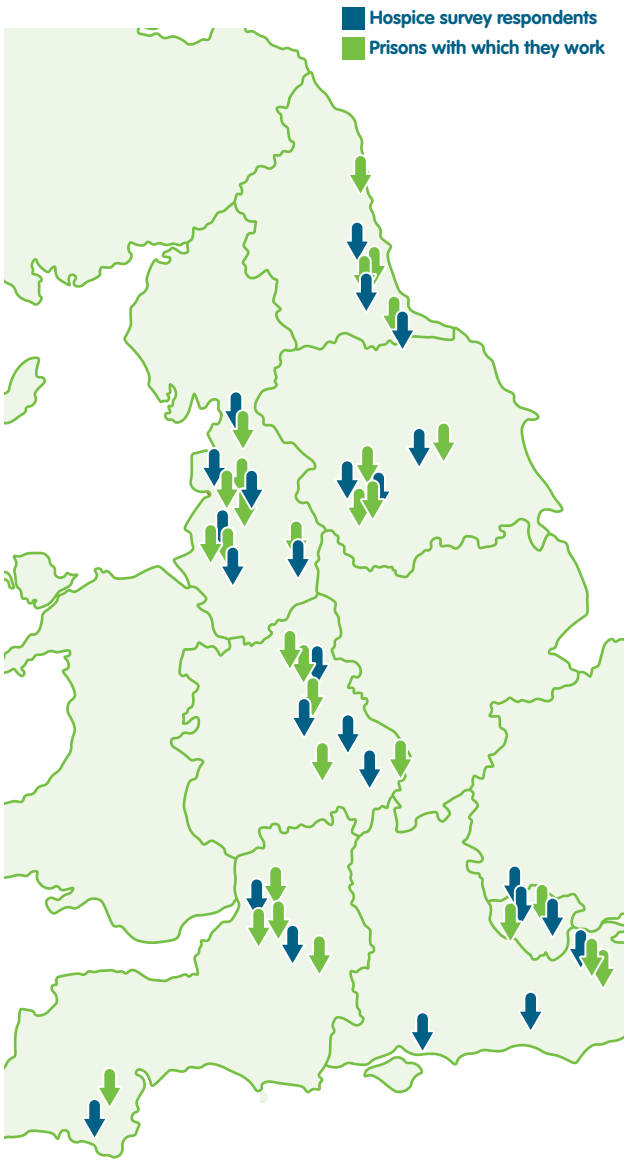
It's not difficult to imagine how these factors could lead to poor outcomes at the end of life for racialised communities and for women in prison. Left unchecked, the comparable dearth of specific research and understanding concerning these and other communities with protected characteristics within the prison estate will only lead to preventable distress and poor outcomes.

Recommendation:
The Prisons and Probation Ombudsman should conduct an in-depth review of natural, foreseeable deaths of those with protected characteristics in prison.

Current state of affairs:
Hospices in England supporting imprisoned people at the end of life

Prior to conducting research for this report, Hospice UK had an anecdotal awareness of the important work that some hospices were engaged in to support imprisoned people at the end of life, but the scope of this provision had not been established at a national level.

Figure X: Map depicting the geographical spread of hospice care provision in prisons



After conducting a survey of hospice services in England, issuing subsequent calls for information, and interviewing executive and clinical hospice staff, we were heartened at the volume and breadth of results.

We found that 25 hospices are providing this care, working with a total of 34 prisons across the country.

This demonstrates that at least 15% of hospices in England are engaged in this important work. The support they provide ranges from providing on-demand specialist palliative care advice to prison clinicians, to directly caring for imprisoned people within the prison estate and hospice in-patient units. Some services have been conducting this work for over 15 years, while others are at the beginning stages of establishing relationships with their local prisons.

Survey findings:

Of the respondents (84%) working with prisons:

65%
are providing on-demand end of life care advice to prisons



62%
are providing direct clinical care to people in prisons



54%
are providing end of life care teaching and training to prison staff



"People in prison have just as much right to come to the hospice as people from hospitals, care homes, or their own homes."

Interview excerpt, Paul Marriott, Chief Executive of St Cuthbert's Hospice

Findings: beyond the figures

The responses we received gave us a critical insight into the challenges that hospice care providers face and key considerations they have to account for when providing this much needed care.

1. The power of misconception

A recurring theme that came through from our conversations with hospice care providers was the ingrained misconceptions surrounding hospice services, with multiple respondents citing that the prisons they had encountered were not fully informed of the breadth of services hospices can offer.

This is, unfortunately, in keeping with general public perception: a third of those surveyed think hospice care is only available in a hospice building and only 45% correctly identify that hospice care is available in community settings such as at home or in a care home.

"At the beginning, [the prison's] view of hospices was 'it's just a building, it's just for people at the end of life with cancer,' so the first education session was around what we do."

Interview excerpt, Maddy Bass, Head of Nursing and Quality, St John's Hospice

Combined with entrenched cultures within the prison estate, this can make it difficult for providers to offer their services.

It's important, however, to note that these misconceptions can occur for both parties. Respondents also cite hospice staff's negative perception of imprisoned people as a barrier to providing care, as well as the perceived barrier posed by the presence of prison security staff when treating an imprisoned patient.

"When you first go into a prison, it's quite nerve-racking, you don't know what to expect. Having established prison experience goes a long way to make you as comfortable as you can be in that setting […] The prison hierarchy can be difficult to chip away at."

Interview excerpt, Kate Heaps, Chief Executive of Greenwich & Bexley Community Hospice

2. Incarcerated people are not a monolith: their wishes and agency must be respected

Respondents also underlined the importance of recognising that incarcerated people are not a homogenous group; their needs and wishes at the end of life can vary just as much as those outside of prison. For some patients, dying outside of prison, at home, hospital, or a hospice will be an important wish.

For others, however, prison is their home, and their fellow incarcerated people are their chosen family, making prison their preferred place of death. While this might be difficult to understand for those outside the secure estate, respecting the wishes of those at the end of life is of paramount importance and a key tenet of good end of life care practice.

"They know their cellmates, they consider their fellow prisoners as family […] You have to think outside of the box and think creatively how you're going to deliver that care."

Interview excerpt, Helen Brewerton, Head of Community Services, Royal Trinity Hospice

This is frequently noted in the FIRs:

- **F5:** Prison staff had started the application process for the patient's early release on compassionate grounds a year before his death. However, towards the end of his life, the patient decided he would prefer to die in the prison rather than a hospice and the process was discontinued.
- **F41:** The patient chose to discharge himself from the inpatient unit, preferring to be among his friends on the residential wing. To assist him with his daily tasks and enable him to live as independently as possible, the patient was helped by a fellow incarcerated person who volunteered to be his wing based carer.
- **F56:** The patient expressed a desire to remain on the residential wing sharing a cell with his friend, this wish was respected. However, when his health was particularly bad, he did go to the palliative care suite for respite and his friend was allowed to go there with him for support.
- **F58:** In February 2019, the patient said he would like to be moved to a hospice before he died. Preparations were made, and he was transferred to a hospice on 7 March, three days before he died.

> *"The nurses spoke to one referred prisoner over the phone, he said that he didn't want hospice care, he didn't think he deserved it because of his crimes, he said "this is what I deserve." The nurses felt quite helpless around that."*
>
> **Interview excerpt, Maddy Bass, Head of Nursing & Quality, St John's Hospice**

> *"It has been important for some prisoners not to die in the prison, especially for those with life sentences."*
>
> **Interview excerpt, Allison Welsh, Clinical Services Manager, St Cuthbert's Hospice**

3. Reputational risk considerations

The stigma that imprisoned people face is well-documented.[xivii]

As such, reputational risk is an important consideration for hospices, many of which are independent charities for whom, in England, an average of two thirds of income is procured through charitable fundraising.[xiviii]

It is interesting, and promising, to note that none of the hospice representatives we contacted recounted receiving negative community pushback for this work.

We do note that this could in part be due to the fact that most do not explicitly publicise it. It appears that internal concerns among hospice staff are more common, but through transparent discussions, this can be overcome.

> *"[Imprisoned people] are a stigmatised group, once you're in that system it's difficult to get out of it, and we have to recognise that."*
>
> **Interview excerpt, Maddy Bass, Head of Nursing & Quality, St John's Hospice**

> *"It's not a traditional fundraising seller, but I think we should be really proud of this work."*
>
> **Interview excerpt, Kate Heaps, Chief Executive of Greenwich & Bexley Community Hospice**

Case study: Handling reputational risk at St Cuthbert's Hospice

A nurse working in HMP Durham contacted St Cuthbert's Hospice following a request from an imprisoned patient to die in a hospice. At the time, the hospice held a position of not accepting patients from prison, most likely originating from reputational risk concerns. Working together with the prison's clinical team and Governor, the Chief Executive put a successful case to the hospice's board of trustees in order to overturn this position, and the hospice started to accept imprisoned people into its inpatient unit.
The discussion was solution-focused, transparent, and established the relationship between the prison and the hospice. There was some initial nervousness amongst hospice staff, but this was overcome by focussing on these patients as individuals, regardless of their prison sentence. Staff are able to express their concerns, and discussion is encouraged.

Recommendation:

It is vital that there is a better shared understanding of the support that is available from hospice services, and the unique needs that imprisoned people will have at the end of life. National organisations and local services should commit to dispelling myths and misconceptions.

4. Risk assessment: the importance of a case-by-case approach

Beyond reputational considerations, admitting imprisoned patients to hospice inpatient units requires in-depth risk assessment. This can help ensure safety and dignity for the patient while also reassuring hospice staff. One respondent detailed the benefits of implementing a detailed, joint Service Level Agreement in order to design out as much potential risk as possible. For example, by compiling an agreed list of visitors, they are able to minimise exposure to risk to both the patient and other inpatients, visitors, and staff; in addition, by stipulating that attending prison officers only visit the hospice in plain clothes rather than uniform, they are able to help ensure the patient's dignity.

Case study: An example of inadequate risk assessment

One hospice reported an instance where an imprisoned patient was admitted without sufficient risk assessment being conducted as a result of inexperience. His presence in the hospice was made known to some local citizens who were connected to the patient's murder victim. The patient was later transferred "out of the area" for both his and everyone else's protection.

5. Sharing knowledge and learning across the hospice sector

End of life care services identified a number of ways in which their work could be supported and amplified.

Survey responses indicate significant appetite for knowledge-sharing; a dedicated community of practice for those currently engaged in work with prisons to enable the sharing of best practice and problem-solving.

> *"There are many hospices proactively working with local partners to ensure that their services are accessible to all those who need us."*
>
> **Interview excerpt, Caroline Mundy, Clinical Community Engagement Lead, St Peter's Hospice**

Other respondents proposed the development of an accessible, tailored end of life care training offering that prison staff could use to help improve their practice. This offering would need to account for the specific challenges they face in delivering this care. For example, as previously stated, some imprisoned people want to die in their residential cells, surrounded by their peers. However, these cells are not designed for end of life care delivery, and room adjustments can be difficult to make.

> *"There is real appetite for education on this, but it has to be developed around a strategic programme."*
>
> **Interview excerpt, Maaike Vandeweghe, Programme Lead, Greenwich & Bexley Community Hospice**

Raising awareness of intersecting issues such as the growing population of imprisoned people with dementia and the need for bereavement care in prisons was also raised. There was a view that by doing so, we could help tackle the stigma surrounding prison healthcare and allay fears that other providers might feel in engaging in this work.

Recommendation:
National organisations should support and facilitate the sharing of good practice across the palliative and end of life care system for those providing care for imprisoned people.

The importance of partnership working

It's important to recognise the work of specialist, local organisations with specific expertise of working within the criminal justice system. Conversations with these organisations providing or supporting end of life care for imprisoned people gave us further, valuable insight into this important work.

These conversations also highlighted the considerable realised and potential benefits of partnership working between hospices and specialist organisations.

"I discussed with the local hospice as I was concerned that no staff were trained to administer pain relief when needed via a syringe driver. I organised hospice nurses to come into the prison to train prison health care staff in pain management and use of a McKinley syringe driver and checking the site and equipment."

Interview excerpt with a prison Buddy, provided by Recoop

Case study: Hanham Secure Health and St Peter's Hospice collaborate to provide education for prison staff in the face of Covid-19

Hanham Secure Health delivers NHS commissioned primary healthcare services to patients within the five prisons in the Bristol, South Gloucestershire, and Wiltshire areas. They strive to ensure these services are of an equitable standard and have equitable accessibility as would be expected in the community.

At the start of the Covid-19 pandemic in April 2020, the Head of Nursing and Allied Health Professionals at Hanham Secure Health, Abi Bartlett, contacted the Education Team at St Peter's Hospice. She explained that prison staff were anxious at the prospect of having to deliver end of life care within the prison setting in a climate exacerbated by Covid-19. There were specific anxieties around: managing multiple patients at the end of life, personal protective equipment, medication shortages, and symptom management.

St Peter's Hospice's Education Team held a virtual training session for healthcare staff working in all five prisons in the area with no experience of delivering end of life care. This session was very well received: "anxieties were so high prior to it, but after, they were much more comfortable around the prospect of delivering end of life care." (Abi Bartlett).

Case study: Recoop's Buddy Support Worker training programme

Recoop is a charitable organisation that has been pioneering new and effective ways to support older people in prison. Their flagship Buddy Support Worker training programme trains imprisoned people to deliver health and social care support to fellow people with convictions. The programme was developed for use in prisons by adapting standards from the National Care Certificate, occupation standards that workers across health and social care services adhere to.

Recoop is currently delivering this programme on a full-time basis in prisons across Devon (HMPs Dartmoor, Channings Wood, and Exeter) and the North West (HMPs Wymott, Preston, and Kirkham).

The following examples plainly demonstrate the immensely valuable and compassionate support that Buddies provide to fellow incarcerated people with terminal and life-limiting conditions.

Example 1: Maintaining high standards through palliative care

The Buddies look at all the aspects of health and well-being and try to put something in place to cover everything, for example, fresh air and exercise, meaningful activity, communication with family, nourishing food, discussing menu choices with them, and making requests to healthcare.

A local hospice came in to teach both the kitchen manager, staff, and the Buddies how to prepare different types of soft food diets and how to make a prison meal palatable for someone with swallowing issues.

Before Recoop organised this training, the kitchen tended to send down scrambled egg as a standard meal for anyone needing a soft diet. This, along with pain killing medication, was causing further constipation problems.

Example 2: Providing choices and enabling decision-making

A Buddy with two years' experience on the health and social care wing supported a man with Parkinson's who had lived on the specialist wing for some time. This man had mainly bad days, with the occasional good day, when he could speak. The Buddy, on these days, would ask the man if he would like to phone his wife or daughter and help him with the numbers.

The Buddy would also give him the choice of tea or coffee to drink. As the man could not generally speak, the Buddy would make both and put on either side of the cantilever table and ask which he preferred. The Buddy would then wait for the man to be able to change his gaze to stare at either the cup of tea or coffee, depending which he wanted.

Over the last few months, the Buddy had noticed that he lost weight, had been spending more time in bed, and had fewer days when he could communicate. "He is silenced and locked inside a dying body as if his own body is his prison," the Buddy told Recoop. The Buddy started singing quietly when cleaning his room to try and lift the atmosphere and he noticed that his eyes would watch him closely. Despite his expressionless face, the Buddy had learned to recognise when this man was pleased and when he was uncomfortable. He liked the singing.

Example 3: Advocacy and monitoring and reporting change

A Buddy has been supporting a man for 18 months, since before he was diagnosed with terminal bone cancer. The Buddy had provided support and advocated for him in meetings with the prison medical team, helping him understand all he wanted to know about his prognosis and taking notes for him. Through this, he had an insight as to how his illness might develop and was in a good position to talk through the answers and comments from the medical team with him whenever he wanted to.

Both liked to play Scrabble and often had a game in the afternoon. Talking was easy, the man had a lot to talk about. He had a new girlfriend just before being sentenced and she was visiting him regularly, and despite pain management being a constant battle, his spirits remained impressively high. He was hoping to be released on compassionate grounds when he became too ill. His wish was to die in his girlfriend's arms.

The Buddy had seen the man deteriorate over the months and was able to report to health care and wing staff that he was becoming very thin and that he thought he had a yellowing to his skin in the morning light. The concern raised by his Buddy was followed up with the man going out on a hospital visit where he was admitted as an inpatient.

Recommendation:

Hospice services should assess the need for palliative and end of life care support for imprisoned people in their community and proactively engage and work closely with local specialist organisations supporting prison health and care services to ensure that need is met.

Concluding remarks

This report confirms the sad reality that there is considerable unmet need for high-quality end of life care within prisons across England. Currently, living with and dying from terminal and life-limiting conditions within the secure estate is an unacceptably variable experience.

While there are hospice care providers and specialist organisations providing excellent care and support to those dying behind bars, this is by no means standardised on a national level. This makes for even more concerning reading in the context of the COVID-19 pandemic, where we know that those both incarcerated and working within prisons have faced immense challenges.

The findings within this report represent a significant opportunity for us all to champion the rights of a much-maligned population. We strongly believe that everybody deserves high-quality end of life care, irrespective of circumstance or setting.

Recommendation: End of life care for imprisoned people should be a UK-wide policy priority. The current provision of and unmet need for end of life care in prisons should be established across the four nations.

Methodology

A mixed methods approach was adopted to meet the aims of this report. By engaging with internal and external stakeholders, a broad range of perspectives were used to inform the final report recommendations.

Primary

Mixed qualitative and quantitative:

Documentary analysis of Prisons and Probation Ombudsman Fatal Incident Reports

The Prisons and Probation Ombudsman (PPO) investigates all deaths in custody throughout England and Wales. The resulting Fatal Incident Reports (FIRs) contain the detail and conclusions of these investigations and are essentially written accounts of the imprisoned people's deaths. Documentary analysis is useful when direct observation is not possible, [xiix] in this case, due to ethical considerations and security barriers to conducting on-site research in prisons.

Mixed qualitative and quantitative:

External, open and closed question surveys to Hospice UK member hospices in England

A survey was distributed to Hospice UK's 174 English members. The survey was designed to gauge: the number of hospices working with prisons, the nature of the care they provide, and their experiences, to inform how Hospice UK can best support them.

Qualitative:

Interviews with Hospice UK member hospices and individuals external to Hospice UK working with imprisoned people

- Semi-structured interviews with individuals from Hospice UK member hospices,
- Conversations with external individuals working with imprisoned people

Qualitative:

Literature review

A range of publications were consulted, including government statistics and academic research, examining the ageing prison population and end of life care provision in prisons.

Ethics

The FIRs identify the deceased by name and contain comprehensive detail regarding their medical histories and the circumstances in which they died. The General Medical Council have clear guidance on maintenance of a patient's confidentiality after death, stating that unless there is a clear imperative to disclose information, the confidentiality of a patient should be maintained after death.[liii] While this information is publicly available, the FIRs have been anonymised for this reason and out of respect for the deceased.

All interviews were conducted via telephone and minuted throughout, following verbal consent from participants to include resulting notes in this report. Survey respondents also provided written consent for their responses to be included in this report.

Limitations

Due to resource constraints, this report focuses exclusively on Hospice UK's English member hospices. This report recommends undertaking further research in all of the UK nations to establish a UK-wide understanding of provision.

The survey, and following interviews, were conducted during the government-advised Covid-19 lockdown. Whilst the response to the survey and requests for interview far exceeded initial expectations, this will have been invariably tempered by the challenging external climate.

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Appendix A: Prisons and Probation Ombudsman Fatal Incident report analysis criteria

These criteria were informed by:

- Discussions with members of Hospice UK's Care and Clinical Leadership team and clinicians external to Hospice UK with experience working within secure and detained settings
- Hospice UK's definition of hospice care
- The Gold Standards Framework
- The Dying Well in Custody Charter Self-Assessment Tool

Evaluation of outcomes for an imprisoned person at the end of life:

A Fatal Incident report meets these criteria if the outcome is explicitly stated in the descriptions of the imprisoned person's care or the final recommendations issued by the Prisons and Probation Ombudsman investigator(s) and clinical reviewers.

Positive outcomes

"Equivalent care"

Pre-existing conditions well managed

Advance care plan in place

Appropriate use/non-use of restraints

Good emergency response

DNACPR discussed and in place

Explicit consideration of the imprisoned person's wishes

"Appropriate consideration of compassionate release"

Next of kin promptly notified

Negative outcomes

"Inequivalent care"

Poor management of pre-existing conditions

Inappropriate use of restraints

Clinical shortcomings

Delayed transfer to hospital

Delayed call of medical emergency code

No advance care plan in place

Non-consideration of the imprisoned person's wishes

Delayed/no consideration of compassionate release

Poor communication

Poor record-keeping

Delayed notification of next of kin

Next of kin inappropriately notified

Security/safety concerns

A of case of particularly good or poor practice is determined by the number, details, and the detailed severity of the above outcomes described by the Prisons and Probation Ombudsman's investigator(s) and clinical reviewers.



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